

Library engagement in exploring polio stories of polio survivors in North central Florida

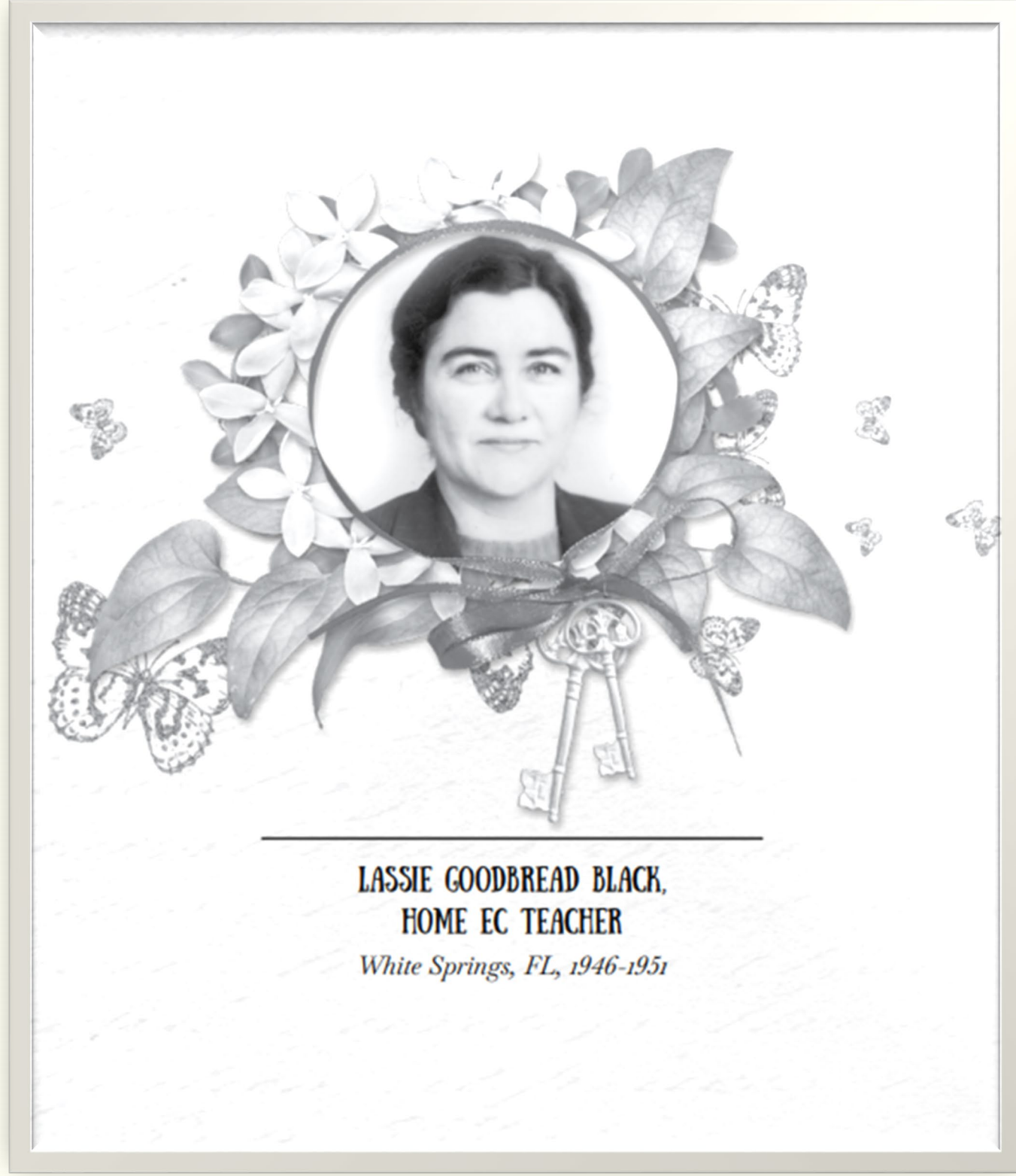
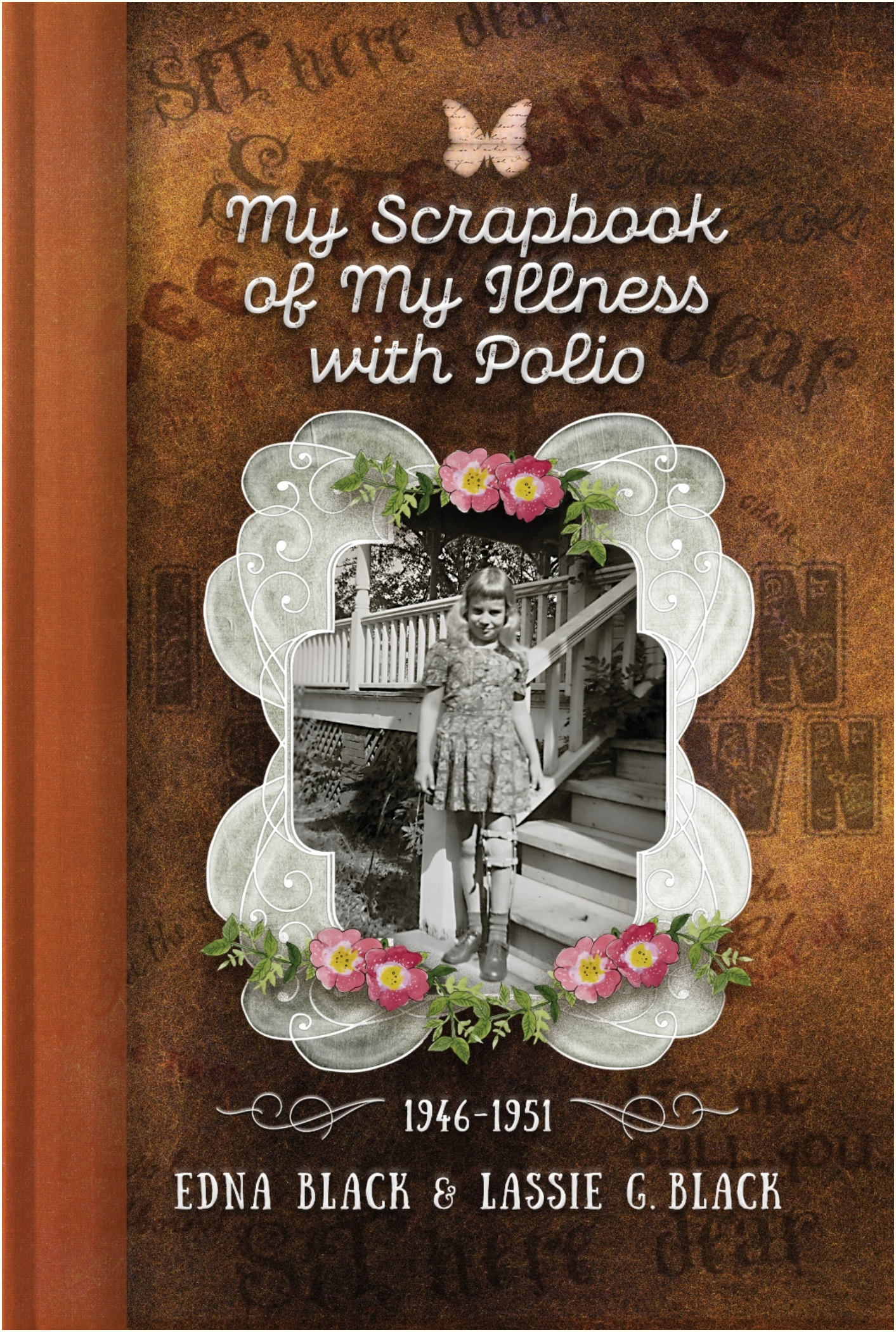
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Introduction/background:

This project seeks to record stories of individuals who survived polio in the 1940s and 1950s in order to capture a unique moment in history, both in how polio impacted society- uniquely and similar to other disease outbreaks, and how individuals with polio negotiated their polio identity and told their story (or remembered through stories told by others).

For the former, infectious diseases can have a tremendous impact on culture, psychology, and the physical structure of society during the course of outbreaks and epidemics. Indeed the form of response often is similar from outbreak to outbreak, as people respond with fear to drastic and devastating changes to the social fabric. Much of this impact, however, can quickly be lost when the epidemic is over and life returns to normal. Even if it is a new normal, the response is to find stability and stories of life with the threat of disease fade from public consciousness. The concerns are that lessons are never remembered and the fear and panic from past epidemics can be repeated. This Polio story project aims to capture the experience of individuals and a society of a lost time, when polio instilled fear in families every summer in the early to mid-20th century. The story is unique in some ways to the biology of polio and the culture of the time, but also part of an old story of human fear and panic.

In addition, stories of people who survived polio lived through the collective experience and confronted the life changes that polio caused for them. Telling their story provided an opportunity to take control of who they were or who they became, and to write and rewrite stories of trauma. For many polio survivors, that story also involved navigating a world of physical barriers and advocating for inclusion and accessibility.

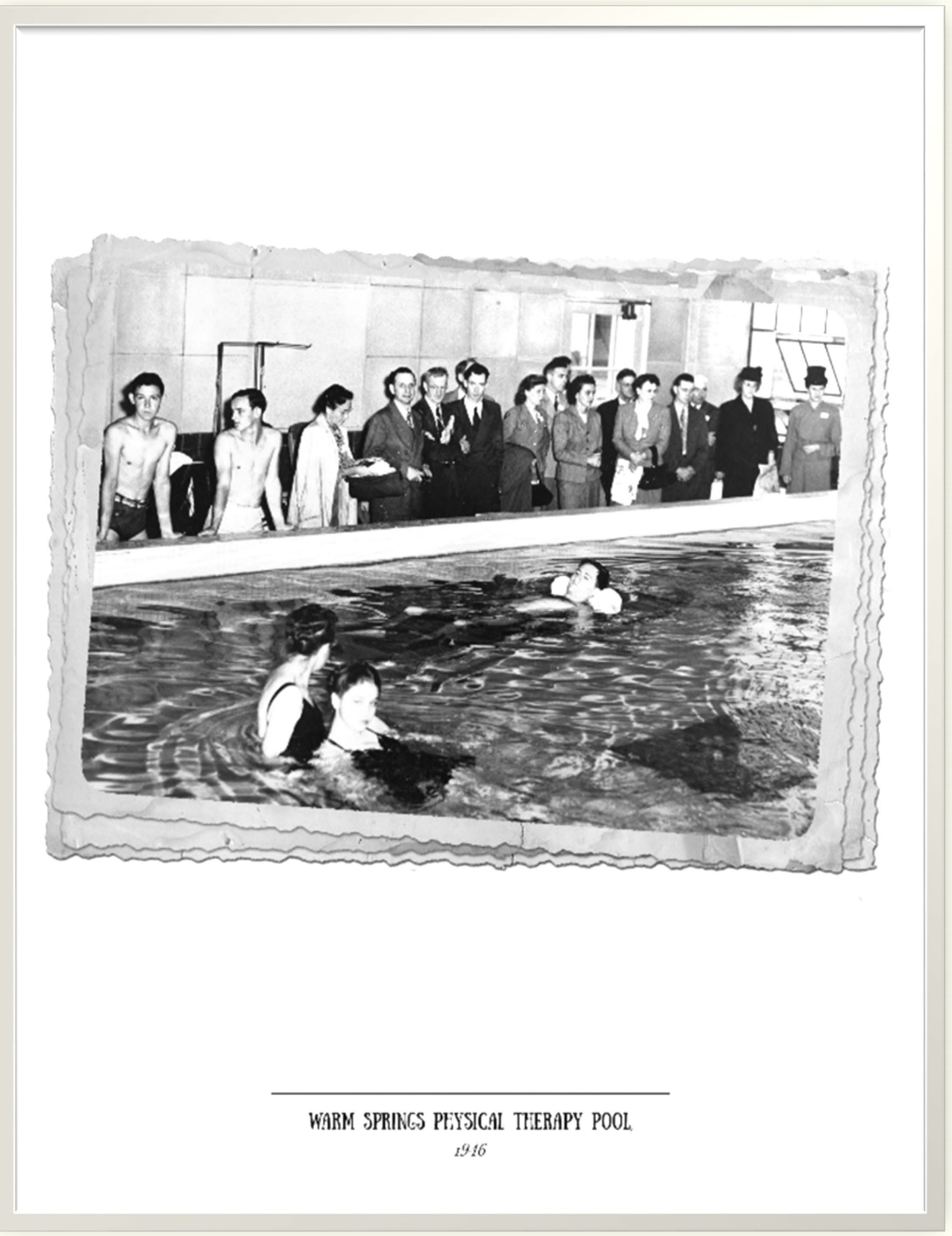
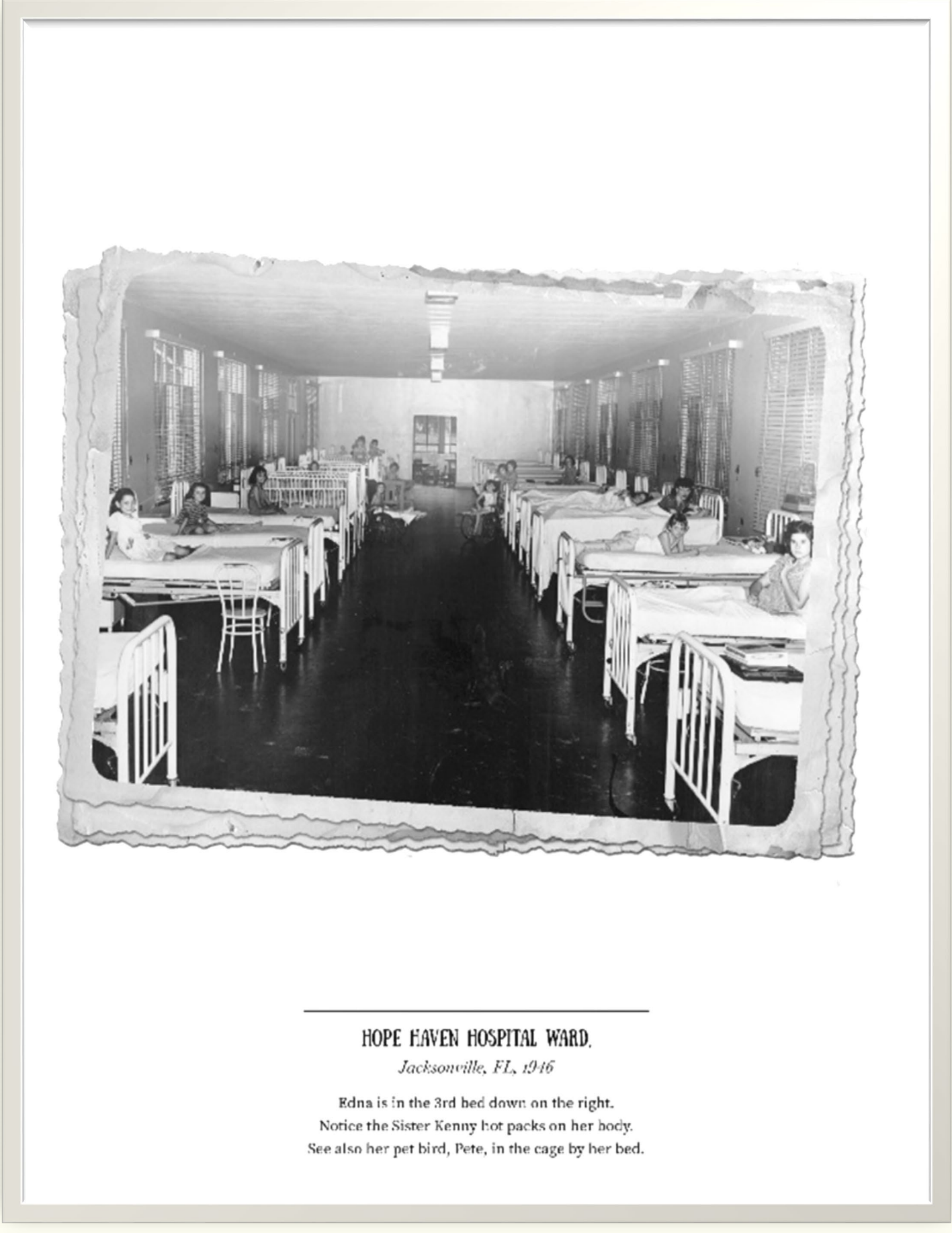
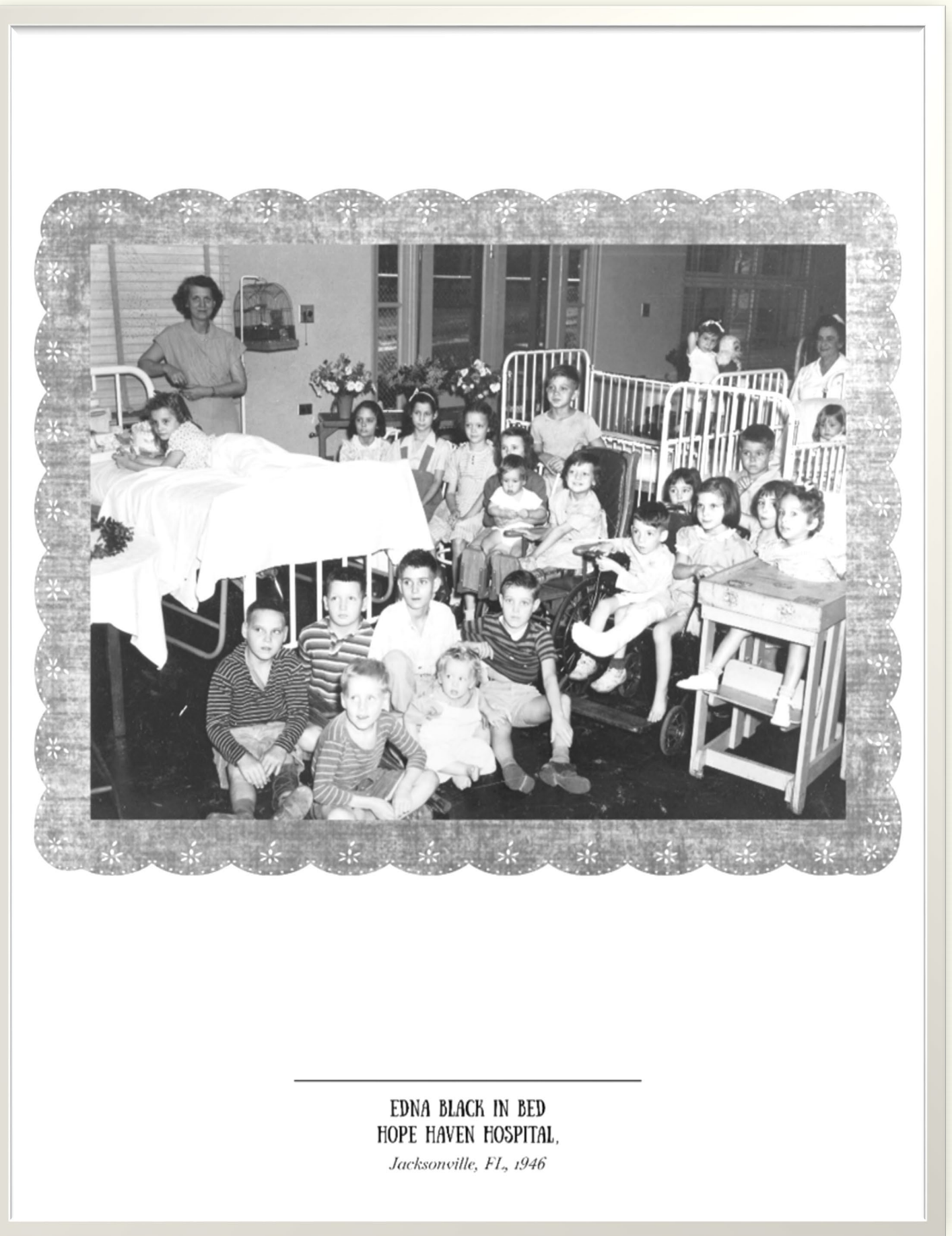
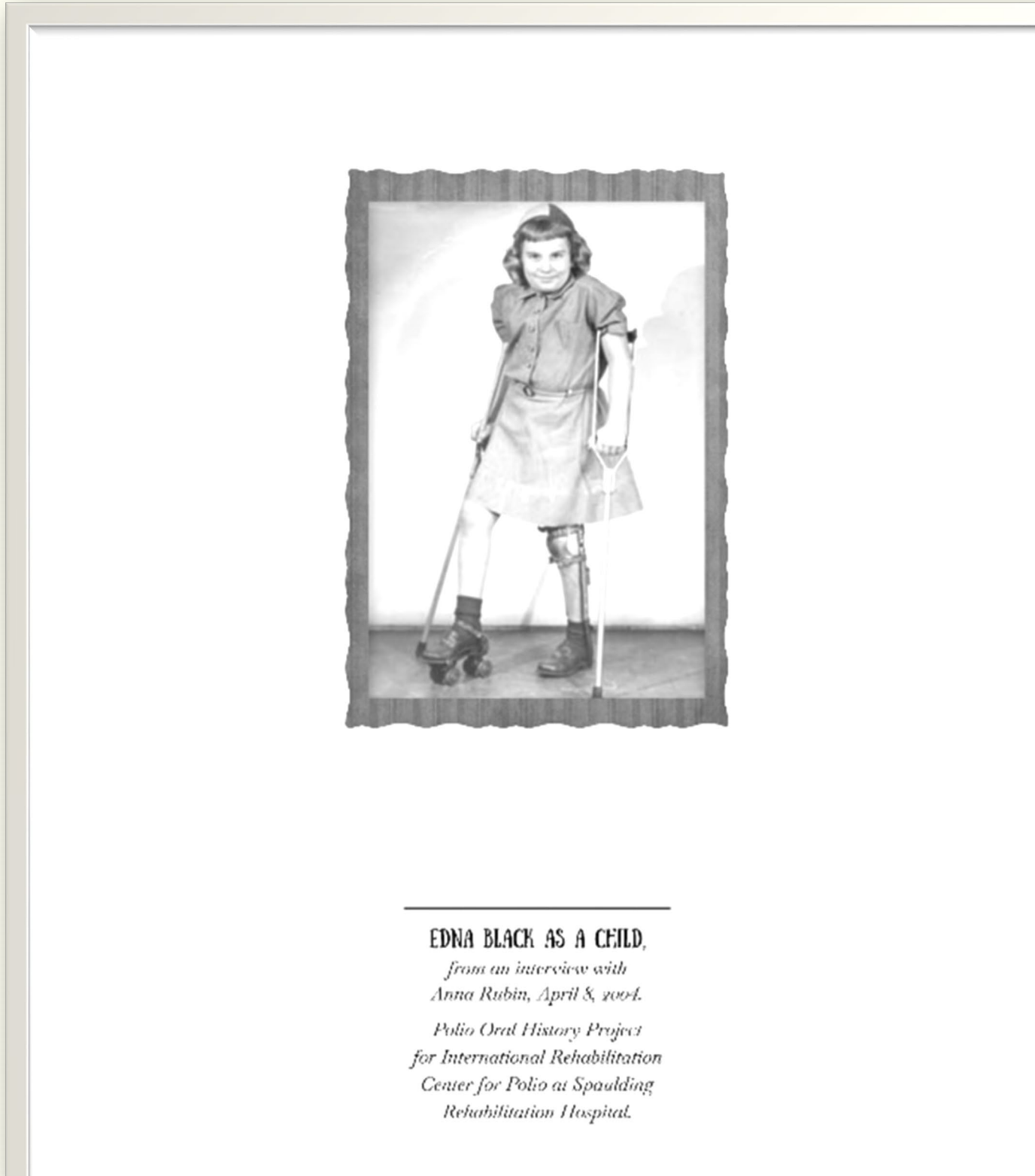


Objectives:

The project represents a library outreach role in developing projects that capture history through oral history, recording stories of illness- in this case, polio. The UF Health Science Center Library historian worked with a Post Polio group in North Central Florida to connect with polio survivors and develop a collection of stories of personal experience, transcribed by the Samuel Proctor Oral History Program. These stories will become part of the University of Florida's Digital Collection on the Proctor Oral History Program site, and made available through the UFDC webpage. The library's engagement in the project also includes publication of a unique manuscript, through the UF Library Press and promotion of a video oral history, with plans to find funding for more videos.

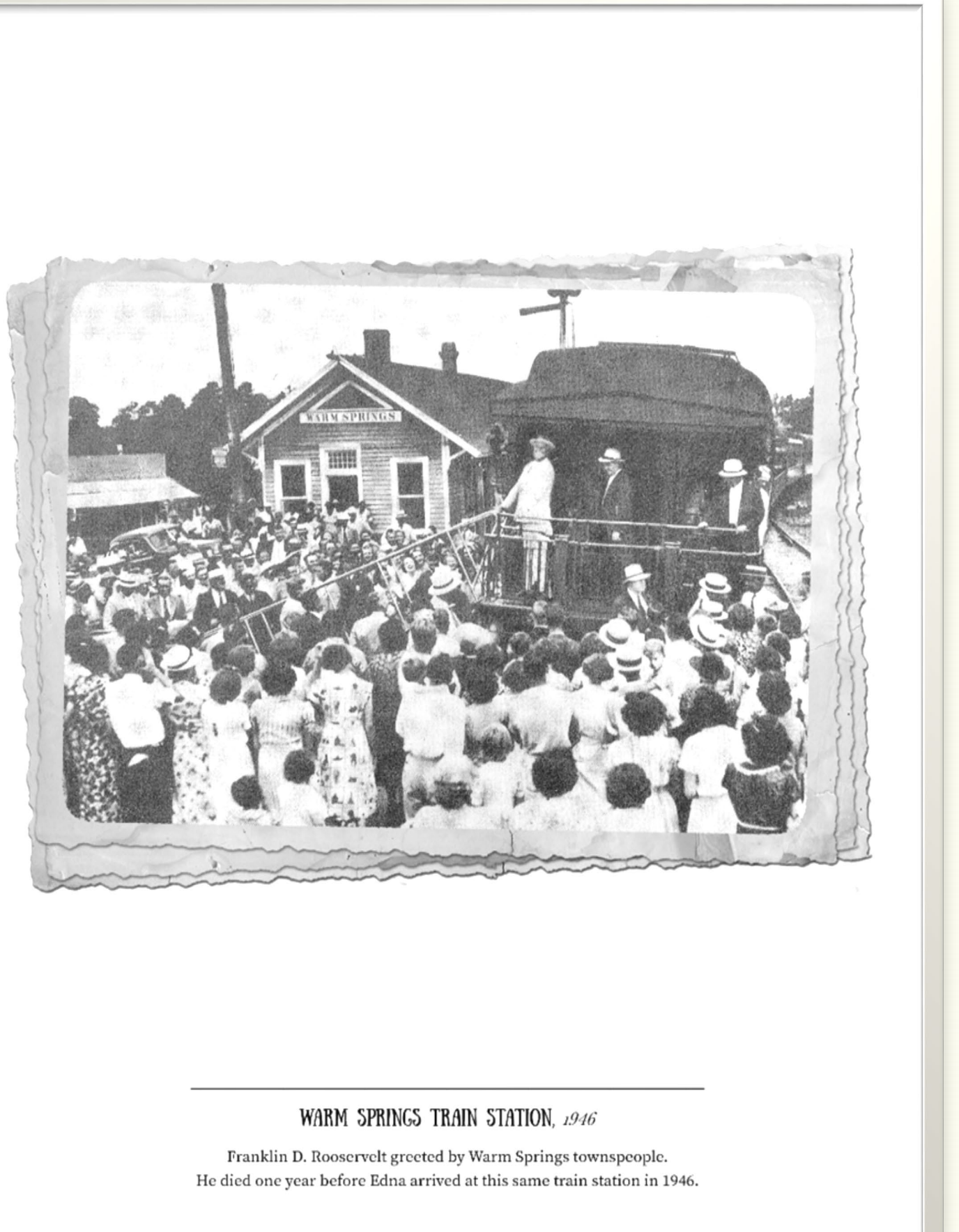
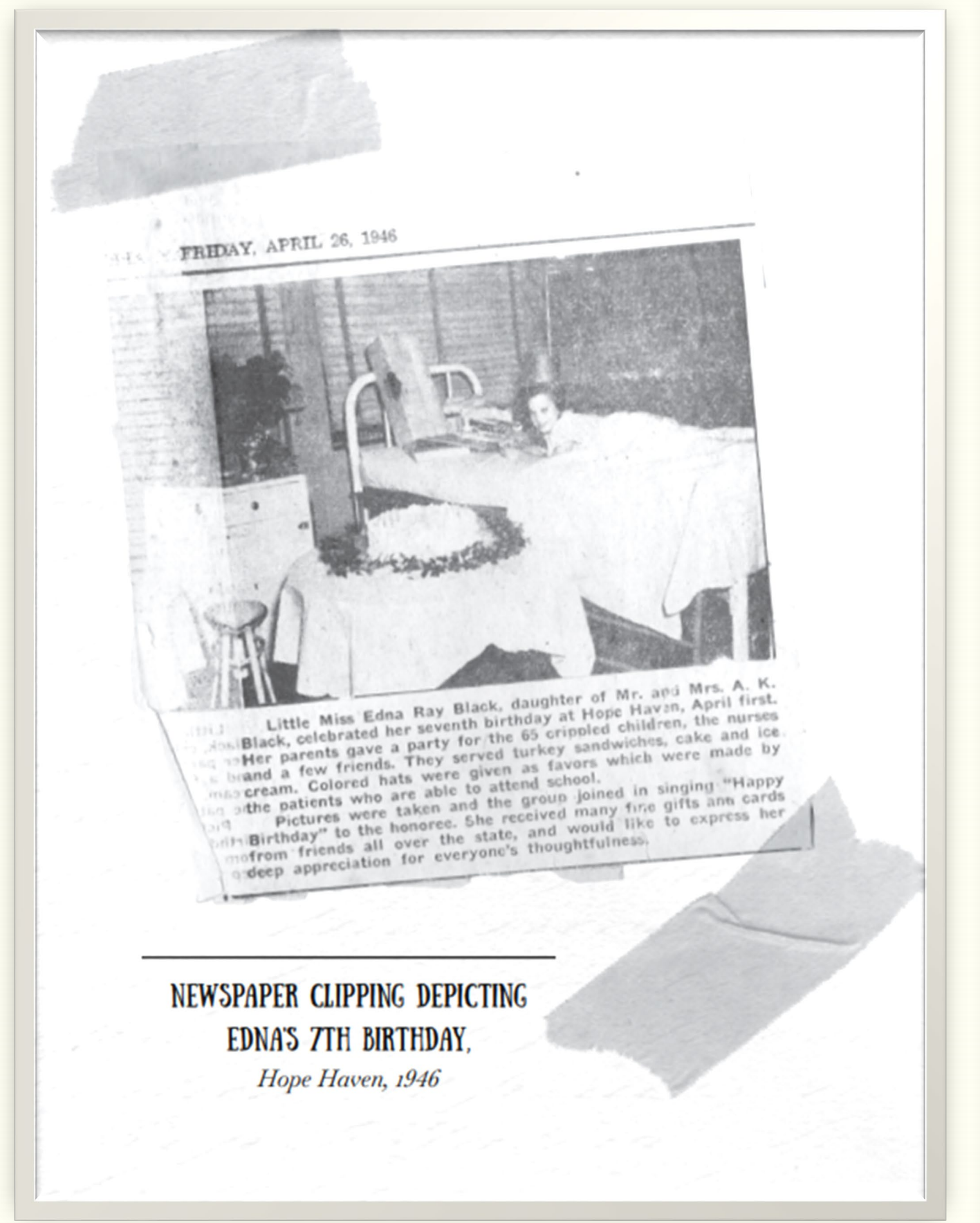
Methods:

This presentation discusses a UF library outreach project to capture stories of polio from people who were children in the 1940s and 1950s, and it includes conducting oral histories, preserving those stories and making them accessible, and working to publish manuscript material capturing experiences with polio. Oral history interviews were and still are being scheduled and recorded. The Smathers Libraries at the University of Florida, through a publication decision made by the UF Library Press, also published the daily journal kept by LASSIE Goodbread Black, mother of polio survivor Edna Black Hindson that detailed Edna's daily experiences as she recovered and lived with outcomes of paralytic polio.



Results:

The efforts to create a polio oral history project at the University of Florida, includes identifying interested individuals, conducting interviews, transcribing materials, creating long term storage for the collection, finding other means to highlight stories and provide materials for understanding the impact of polio and other infectious diseases. The published book of Enda Black Hindson's experience with polio is available as a pdf at <https://ufdc.ufl.edu/AA00069222/00001> A print copy of the book can be purchased at <https://upf.com/book.asp?id=9781944455095> . A video interview with polio survivor, author, former NPR commentator and publisher, Shelley Fraser Mickle can be found at <https://www.youtube.com/watch?v=Nfy4XUTW9SU> Transcripts of other interviews will be posted to the UFDC as they become available and as more interviews are completed.



Characterizing Polio in (Pre) History and History: It is believed that paralytic polio is an ancient disease, with pictorial evidence from the Egyptian 18th dynasty (1403-1365 BCE), with a stele from that period showing a priest with an apparently withered limb possibly resulting from paralytic polio. Other paintings show children walking with canes. Early written reports support the supposition that Roman Emperor Claudius walk with a limp because a polio infection. It also is believed that Sir Walter Scott may have lost use of his right leg due to a "teething fever." This history, of course, only shows us examples of that paralytic polio. Polio infection also can manifest with flu-like symptoms, which is much harder to detect in historical records. Whether an individual develops the paralytic or the flu-like syndromes may depend on age, or maternal antibodies. So records of apparent exposure to and paralysis from polio do not show everything about how frequently populations were exposed to the virus (which spreads through the fecal-oral route). It just lets us know that humans lived with and around polio for millennia, as long as populations were large enough for continuous infection maintaining the virus permanently.

As polio epidemics became more common in the 19th century, Western biomedicine began to characterize the disease. It was recognized as a contagious disease in 1905 and the virus was discovered in Vienna in 1908. The nature of human immunity to polio virus was researched in 1910 by Simon Flexner, who explored how antibodies could combat infection. His continuing work helped researchers focus on antibody production and possible vaccines, and the search for a vaccine was well underway by the 1930s.

OutBreak: epidemic polio in America: Outbreaks of paralytic polio in America became regular in the early to mid-20th century. Outbreaks were more frequent in the summer and came through towns every few years, generating terror among families and changing the social order in a number of ways, from summer municipal pool closings, to mobilization of society to fund polio research by sending dimes to the White House.

Reasons for this increase in paralytic polio epidemics are thought to have occurred because of the rise of urban sanitation: clean water supplies, street cleaning, regulations concerning milk supplies, child labor, housing- the whole range of late 19th and early 20th century reforms that contributed to this increasing sanitation. At the same time many diseases associated with filth such as cholera and typhoid, began to decline- polio stands out as the exception. Why?

The younger someone is when exposed to polio, especially under four years old, the less likely they are to develop paralytic polio (and they may have some maternal antibodies). Increasing sanitation meant that children were exposed for the first time at an older age.

The earliest recorded epidemics were small, and in different parts of the country. Small outbreaks occurred in Louisiana in 1841 with 8-10 cases and New England in the 1890s. A 1910 epidemic in Washington DC resulted in 16 deaths, with 506 reported cases. The impact of polio, however, began to increase with a major epidemic in New York City in 1916, resulting in 2,343 deaths out of 9,000 cases. In 1916 polio was believed responsible for 6,000 deaths and after that, polio outbreaks were a regular part of American summer life.

In 1921, Franklin Delano Roosevelt, then 39, was struck by a paralytic illness then diagnosed as polio His paralysis was permanent, and he spent his later political career hiding it. His family and advisors encouraged him to reenter public life, with a successful gubernatorial race in of New York in 1928. He was elected president, and was reelected for 4 terms. As he recovered from polio, he visited Warm Springs in Georgia in 1924- later the site of "The Little White House" in 1932. And Warm Springs became the national home for polio rehabilitation and research in 1927, now known as the Roosevelt Warm Springs Institute for Rehabilitation. As polio became even more widespread, Roosevelt also founded the National Foundation for Infantile Paralysis in 1938, and encouraged Americans to send their dimes to the White House to help fund research. Later renamed The March of Dimes, this foundation was successful in raising funds and helped to further research toward a vaccine, first the Salk vaccine- an injection of the killed virus, approved in 1955, and later the Sabin vaccine, an attenuated vaccine given orally, which was approved in 1961.



Conclusions:

Polio certainly impacted thousands when it was epidemic in the United States. An estimated 35,000 people were paralyzed each year in the 1940s. In 1952, an estimated 60,000 were infected, with more than 3,000 deaths. In terms of sheer numbers, it affected fewer people than tuberculosis or cancer. In terms of the fear it created, and the impact it had on society, it was unprecedented. Although adults could be affected, the fact that it struck many children, leaving those who survived paralyzed to a greater or lesser degree, mobilized the nation, leading to publicly funded research initiatives, and an invigorated movement to provide equal rights and access for those with disabilities. Caring for survivors impacted society; but survivors themselves worked to transform their world- leaving stories of struggle and triumph. The story of Edna Hindson's experience, told in a unique way, helps to bring back an understanding of the disease's impact. Infectious disease outbreaks have shaped human history, just as those impacts, or at least the psychological impacts of living with fear and uncertainty of disease spread are quickly forgotten. This project highlights the impact of one particular disease, polio, in the South through the words of survivors. The role and neutrality of a library facilitate outreach and connection with individuals who wish to share their stories.

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